



Chest Heart & Stroke Scotland

In partnership with

Scottish Pulmonary Rehabilitation
Action Group

2017 Pulmonary Rehabilitation Survey



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Scotland



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Introduction

People living with a long-term lung condition are amongst the biggest users of health services in Scotland, with over 129,000 people diagnosed with COPD (chronic obstructive pulmonary disease). There are over 19,000 hospital admissions each year due to COPD, and 129,300 beds days accountable to the diseases¹.

Pulmonary rehabilitation (PR) is proven to be clinically effective and is one of the most cost-effective treatment options available for COPD, reducing both the number of bed days and hospital admissions^{2,3}. A growing body of evidence shows it is also effective for other respiratory conditions such as bronchiectasis and idiopathic pulmonary fibrosis^{3,4}. PR is an essential element of integrated care and support, as it offers exercise training, education, advice and support^{2,3,4,5}. Health guidance recommends it is provided by the NHS as a fundamental treatment option for people living with long-term lung conditions.

Lung rehab has been shown to reduce breathlessness, increase fitness, and improve overall quality of life. It supports people to live as independently as they can and self-manage their condition. If adequately resourced, PR can help to address health inequalities by providing a highly effective intervention for health conditions which have a strong correlation with deprivation^{2,3,4,6}.

Until now there has been little data available about the provision of PR services in Scotland, including whether they meet clinical guidelines. There has been no opportunity for comparison by health professionals or patients which could highlight variations or areas of effective practice. This survey was undertaken by Chest Heart & Stroke Scotland, a neutral organisation working to promote the importance of this service on behalf of the Scottish Pulmonary Rehabilitation Action Group (SPRAG), a multidisciplinary, national group promoting the value of PR. It provides information on 11 out of 14 regional health boards' PR services. The results show that where PR provision exists, the content is consistent across the country with similar exercise and educational information. However the results also highlight variation in the capacity and delivery of rehabilitation.

Key findings

- Pulmonary rehabilitation programmes are not available across all regional health boards. The programmes which are provided vary widely in format, capacity and delivery, both between and within health boards.
- Approximately 9,000 places per year are available on pulmonary rehabilitation programmes. This is significantly lower than the estimated 69,000 which are needed.
- Many people who would benefit from rehabilitation are not being referred by their GPs; more research is needed into the reasons why.
- Waiting times to begin rehabilitation range from 2 to 26 weeks, although most start within the recommended 3 months. Following an exacerbation of COPD the recommended referral to rehabilitation is within 1 month, but only half of services can meet this target.
- A significant proportion of people referred to rehabilitation are not completing their programme, which is a reflection of the physical and practical challenges people face when living with chronic lung disease.
- Only one programme has input from a clinical psychologist, despite the well-documented link between anxiety, depression and long-term respiratory conditions.
- Developing exercise plans for people after completing their rehabilitation programmes encourages continued exercise, but only half of rehabilitation programmes provide plans.
- The benefits of rehabilitation can be lost within 6-12 months if people do not remain physically active. However, although all rehabilitation services can refer or suggest options for ongoing support, only two-thirds of programmes include monitoring of longer-term outcomes.

Recommendations

1. Increasing investment in PR across all health boards to meet local need. This would enable net savings to be made through reduced hospital readmissions, and support the national strategic shift towards community-based self-management.
2. Raising awareness of the benefits of PR among health and social-care professionals and the public. This would improve rates of referral, participation, and completion of PR programmes.
3. Actively addressing the barriers to referral and participation.
4. Incorporating a transition to community exercise maintenance and support.
5. Creating a national dataset about the provision of PR. Robust and regular data collection would benefit service users and providers, by enabling benchmarking, sharing of best practice, and informing further service developments.

SECTION 1: SURVEY FINDINGS

The figures below have been used throughout this report as a baseline measurement of the levels of need for pulmonary rehabilitation. Not all people with a diagnosis of COPD will benefit from PR – it is most effective for those people who have functional limitation due to breathlessness. PR is likely to be less effective when other conditions co-exist, such as cardiac instability or significant cognitive impairment (BTS Guidelines 2013).

Table 1: Estimated number of people with COPD who would benefit from PR

Health Board	Prevalence of COPD 2015/16 (QOF ISD)	Incidence (new diagnosis) of COPD 2015/16*	Estimated number of COPD population who would benefit from PR 2015/16**
Ayrshire and Arran	10,719	583	5,651
Borders	2,742	178	1,460
Dumfries and Galloway	4,599	304	2,452
Fife	9,006	667	4,837
Forth Valley	6,962	365	3,664
Grampian	10,157	804	5,481
Greater Glasgow and Clyde	31,956	1,983	16,970
Highland	6,434	475	3,455
Lanarkshire	17,355	1,176	9,266
Lothian	17,400	1,555	9,478
Orkney	372	26	199
Shetland	284	14	149
Tayside	10,607	640	5,624
Western Isles	510	19	265
Total	129,103	8,789	68,951

*As per HIS calculation methodology: (current prevalence – previous year's prevalence) + mortality

**As per HIS 2011 costing report calculation: 50% prevalence plus 50% incidence

The number of people who would benefit from attending PR programmes has been calculated based on methodology used in the 2011 HIS PR costing paper⁷ which combines 50% of prevalence figures with 50% of the incidence figures to give an annual figure. This established methodology is regarded as the most accurate means of calculating the number of people suitable for PR. It does not take account, however, of recent changes to guidelines which recommend that people with milder symptoms of COPD, such as those at MRC level 2, should now also be referred to PR. Nor does it include people living with other long-term lung disease, some of whom evidence shows may also benefit from PR^{3,4,6}.

Availability of Pulmonary Rehabilitation

Health boards provided data on the capacity of the PR services which they provide, and the numbers of referrals which were made to those services. When compared with the population numbers who would benefit from PR, the table below illustrates the scale of potential unmet need.

- Whereas almost 69,000 people need PR, there is capacity for only 9,000.
- Across the regional health boards an average of just 8.4% of people who would benefit from PR receive a referral to a programme.
- There is no PR service available in NHS Borders.

Table 2: Capacity of PR services and number of referrals made

Health Board	Estimated number of COPD population who would benefit from PR**	Maximum capacity of PR services 2015/16 (source: CHSS survey)	Number of referrals to PR (source: SPRAG & CHSS survey)
Ayrshire and Arran	5,651	291	644
Borders	1,460	0	0
Dumfries and Galloway	2,452	381	200
Fife	4,837	520	375
Forth Valley	3,664	Not available	Not available
Grampian	5,481	570	537
Greater Glasgow and Clyde	16,970	1,768	1,985
Highland	3,455	524	111
Lanarkshire	9,266	416	553
Lothian	9,478	1,144	1,296
Orkney	199	Not available	Not available
Shetland	149	Not available	Not available
Tayside	5,624	676	685
Western Isles	265	26	Not available
Total	68,951	8,952#	6,386#

**As calculated in Table 1 above

^Maximum annual capacity was calculated by multiplying the number of programmes that could be offered throughout the year by the weekly capacity of the programme.

#National totals are incomplete due to regions who did not respond to the survey.

There appears to be no clear correlation between usage of PR services and levels of need throughout the country, with variable referral rates in both areas of high and low deprivation as well as urban and rural settings. Many of the health board regions encompass a broad range of population needs and it is beyond the scope of this report to explore beyond regional health boards to community level.

% of PR need exceeding capacity of programmes

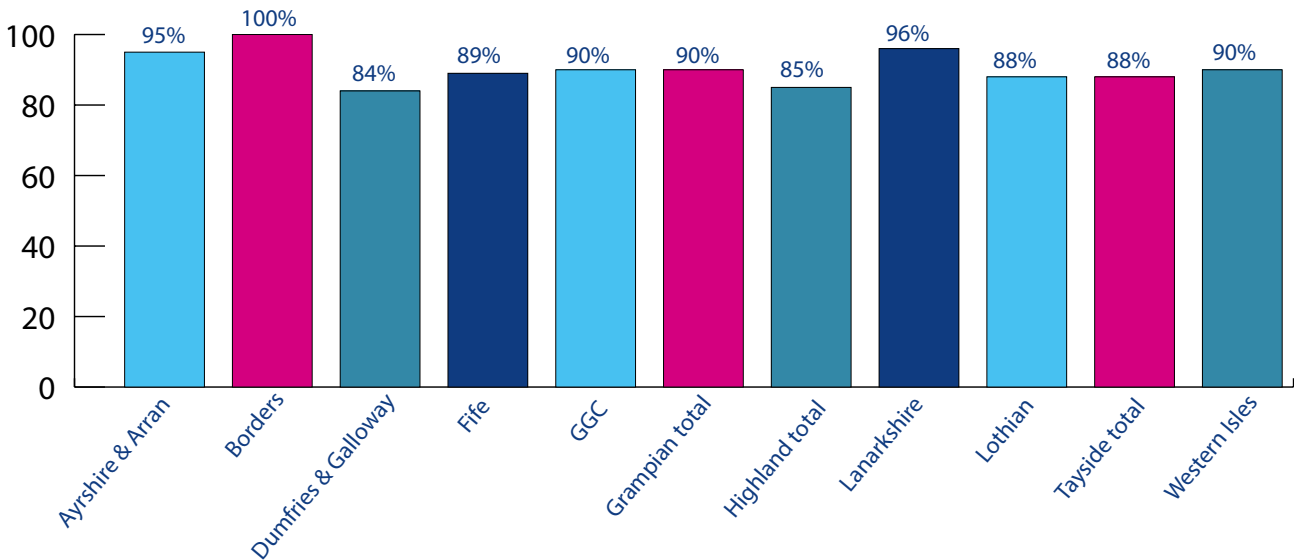


Chart 1: Unmet need – the percentage of people who would benefit from PR but local programme capacity does not currently accommodate.

% of referral rates against PR need

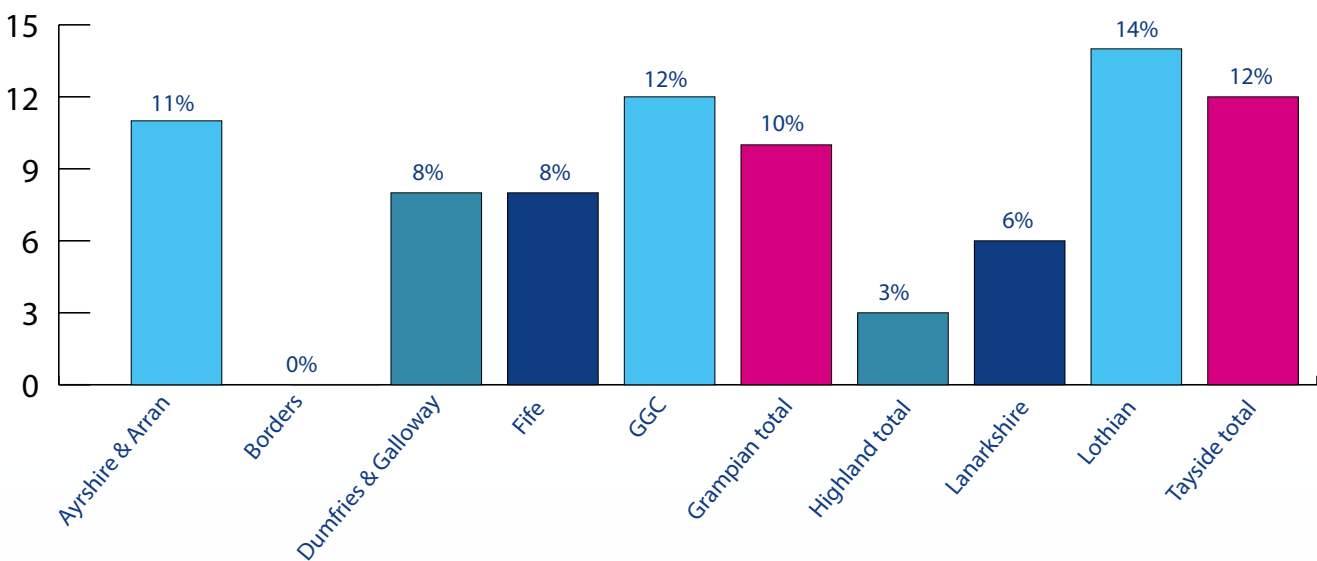


Chart 2: Referrals made to PR as a percentage of those who would benefit.

(Data for NHS Western Isles not available)

The capacity of local PR programmes falls far short of the scale of potential need across all health boards (see chart 1). Most people who would potentially benefit from PR are not being referred to a programme (see chart 2), and it is understandable that service provision responds to the demand evidenced by referrals. This is illustrated in the health boards with the longest waiting times (NHS Dumfries and Galloway, Fife, and Highland) where they also have low referral rates. National guidelines highlight the importance of the referring healthcare professional to be aware of the benefits of PR and so, in turn, to create or maintain demand for services^{5,6,8}.

Waiting Times (weeks)

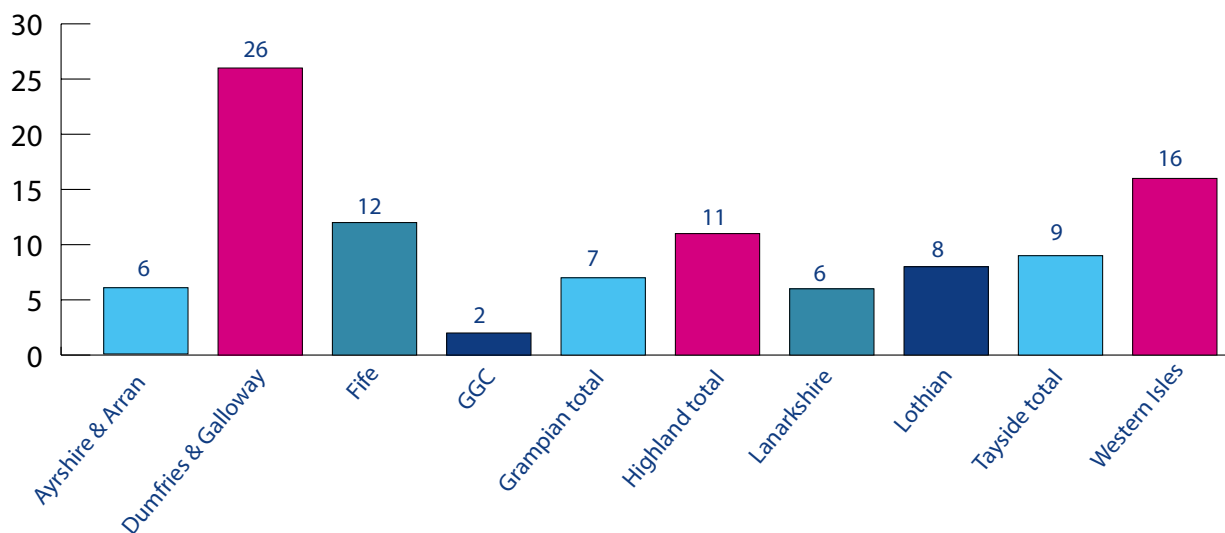


Chart 3: Average waiting times for pulmonary rehabilitation by health board

NB: No PR programmes are provided by NHS Borders.

Waiting times to begin PR programmes are widely variable across the country, but most services meet the national guidelines^{4,8,9} of PR treatment commencing within 3 months of referral.

In areas where the waiting time is longer than 10 weeks, three quarters of PR services structure the delivery of programmes in a 'block' style, where a cohort of patients commence a fixed length of a PR programme. This format is more likely to be in place when resources are limited or are difficult to sustain. If people are unable to complete the programme then their place is left unfilled, resulting in people waiting until the next cohort begins. A more efficient method of providing PR services is to utilise a rolling design where places can be filled if people leave before the course is completed (as recommended by the 2016 national COPD audits⁸).

Levels of completion of PR programmes by patients

- The average completion rate of PR programmes by patients is just over 45%, ranging from 59% in NHS Highland down to 17% in NHS Ayrshire and Arran.

Table 3: Levels of completion of PR programmes by patients receiving a referral

Health Board	Number of referrals to PR (source: SPRAG & CHSS survey)	Number of people completing PR (source: SPRAG & CHSS survey)	Percentage of those referred who completed PR
Ayrshire and Arran	644	109	17%
Borders	0	0	Not applicable
Dumfries and Galloway	200	107	54%
Fife	375	195	52%
Forth Valley	Not available	Not available	Not available
Grampian	537	229	43%
Greater Glasgow and Clyde	1,985	695	35%
Highland	111	65	59%
Lanarkshire	553	123	22%
Lothian	1,296	731	56%
Orkney	Not available	Not available	Not available
Shetland	Not available	Not available	Not available
Tayside	685	382	56%
Western Isles	Not available	Not available	Not available
Average	6,386	2,636	45%

These figures illustrate the well-recognised challenge for PR programmes of maintaining participation once a referral has been made^{3,8}. Low completion rates are a likely reflection of the complex and multifactorial nature of the difficulties experienced by many participants engaging with PR programmes. This is in part due to the unpredictable nature of respiratory health and fluctuating symptoms.

Wider barriers to participation include transport and access to venues, especially when participants have limited exercise tolerance and dyspnoea (breathlessness). The ATS/ERS 2015 statement on pulmonary rehabilitation⁶ comments that travel time greater than 30 minutes is also a barrier to participation in PR.

The 2014 report on person-centred activities for people with respiratory, cardiac and stroke conditions (PARCS)¹⁰ found that barriers to exercise participation included lack of information about programmes, lack of transport, and reduced confidence in participants. The report also identified a common reason for discontinuing with exercise was a resurgence or exacerbation of respiratory symptoms.

PR provision post-exacerbation

- Only 6 health boards currently provide PR programmes within the recommended timescale to people who have experienced an exacerbation.

Provision of post-exacerbation PR

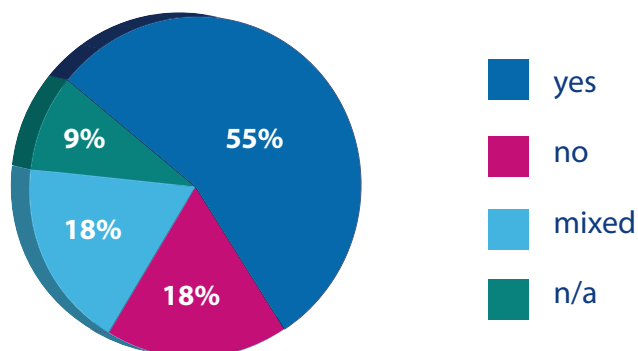


Chart 4: Proportion of health boards providing PR programmes post-exacerbation

An exacerbation of COPD is a sudden worsening of symptoms such as breathlessness and increased mucus, and is a common feature of living with a long-term respiratory condition. Exercise capacity and levels of physical activity are often reduced following an exacerbation, which is associated with an impaired quality of life that can last up to several months, increased mortality and increased healthcare use.

Clinical studies have shown that following an exacerbation, engagement in pulmonary rehabilitation in a 4-week period after discharge from hospital can reduce the risk of future hospital care, improve health-related quality of life and improve exercise capacity.

The most recent guidelines on pulmonary rehabilitation^{2,3,4,5} recommend offering PR within 1 month following discharge from hospital due to an admission caused by an exacerbation of COPD.

PR programme service design

The local delivery of PR services across Scotland has been shaped by local need and varied resources. British Thoracic Society guidelines (2013)⁴ recommend that PR programmes should last between 6 and 12 weeks.

- The average length of programmes provided by Scotland's health boards is 7 weeks, with classes held twice a week.

Longer programmes are run in NHS Ayrshire and Arran and NHS Grampian, with up to 10 classes provided once a week. Two of the health board areas, Highland and Grampian, offered a varied frequency and length. NHS Borders has no PR programme in place.

45% of programmes in Scotland are run as a rolling design. 18% of programmes are run as a series of block programmes and 27% have a mixture of block and rolling design within their health board area, dependent on local need.

The 2016 national COPD audit conducted in England and Wales⁸ suggests that the most efficient form of programme design is a rolling programme which provides greater efficiencies in the use

of resources and results in shorter waiting times. Block or cohort programmes require a minimum number of people to attend as a group. This design is often selected when services are being established or if referrals to the service are inconsistent.

With health boards facing ever-challenging budget constraints, many services have utilised an increased mix of workforce skills and technology.

- **7 health boards employ support workers to assist in the delivery of programmes.**

The National Telehealth and Telecare Delivery Plan for Scotland 2015¹¹ recognises the need to develop a more flexible approach to delivering services to meet the rising demands of Scotland's ageing population.

- **When asked if telehealth was used as a routine part of delivering PR services, only 36% of health boards said that they did.**

Health boards using telehealth include Ayrshire and Arran, Lothian, and parts of Grampian. Surprisingly, the responses suggest that it is not used in other rural areas such as NHS Highland and NHS Lanarkshire.

PR programme content

PR programmes should include a structured educational element in order to support lifestyle and behavioural changes and assist self-management of the long-term condition. National standards recommend that these should be delivered by professionals.⁹

- **Most PR programmes include a broad range of topics within the educational component.**

All programmes provided included information on how to manage breathlessness, inhaler technique, medications and energy conservation. These educational topics were delivered by a varying multi-disciplinary team of health professionals including physiotherapists, respiratory nurses, occupational therapists and dieticians.

- **Only 1 programme had input from a clinical psychologist, despite the well-documented issues of associated anxiety and depression linked to long-term respiratory conditions.**

Psychological input is also one of the recommendations in the NICE 2010 COPD guidelines.

Education Components

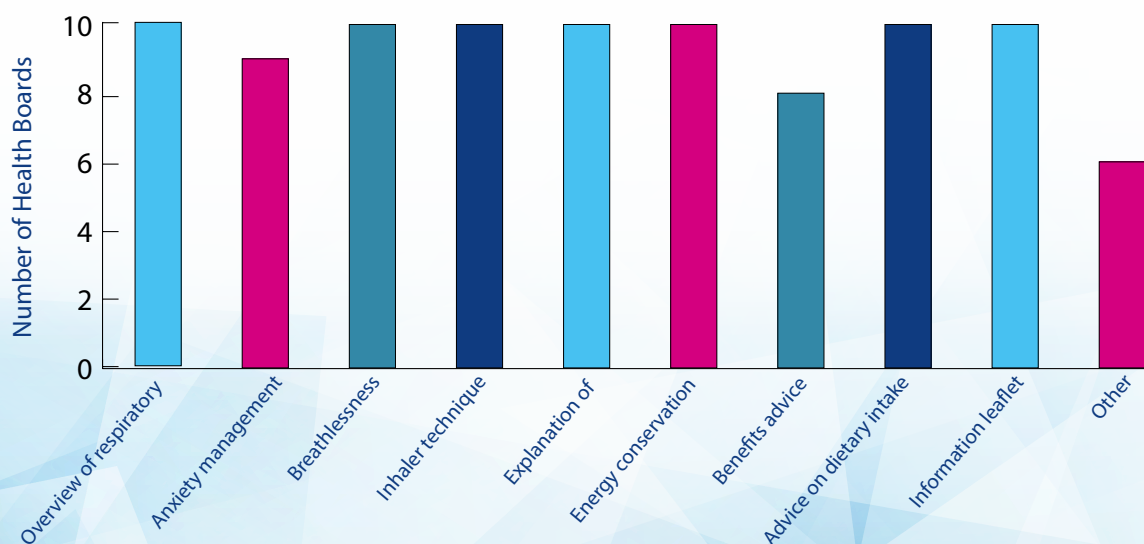


Chart 5: Range of subjects provided within the education component of PR programmes

The exercise component of PR programmes is also vital. Physical deterioration, including breathlessness and fatigue, is common for people living with COPD and other long-term lung conditions. It can lead to a spiral of inactivity and reduced exercise capacity when coupled with the fear of provoking these symptoms further. Not only is there a reduction in physical activity, but changes to skeletal muscle also occur. This commonly results in reduced lower-limb muscle strength, which is a poor prognostic indicator in COPD. BTS (2013) guidelines⁴ recommend that training should include a combination of endurance (such as walking or cycling) and progressive resistance training.

- **All PR programmes offered by health boards meet guidelines in offering a combination of aerobic and resistance training.**

Accessibility and location of services

Ease of access and the provision of services in a variety of suitable locations are key factors in improving participation and completion rates^{2,3}. Of the 11 health board areas that provided information, 4 have rehabilitation facilities across hospital, community and leisure facilities, 4 offer PR in both hospital and community venues, and 2 offer hospital-only based programmes.

The 2015 national COPD audit⁸ suggests that in order to improve accessibility and attendance at programmes, transport should be 'available to patients who find travel difficult and that sufficient flexibility in scheduling of sessions is provided for patients who have other work or family commitments.'

- **Approximately one third of the services that responded to the survey are unable to provide patient transport at all.**

Of the services that are able to provide transport, the facility is limited with strict criteria to be met for eligibility, and the expectation that participants will book their own transport.

Assessment of treatment outcomes

To demonstrate the improvements which PR provides to quality of life, self-management and increased physical activity, the 2014 BTS quality standards⁹ require the outcome of treatment to be assessed, including the measurement of exercise capacity, dyspnoea and health status. Additionally, the 2015 national COPD audit⁸ recommends that services should compare treatment outcomes to enable further improvement. These measurements should be recorded before treatment begins as a baseline at initial assessment and again on completion of the programme.

Outcome Measures

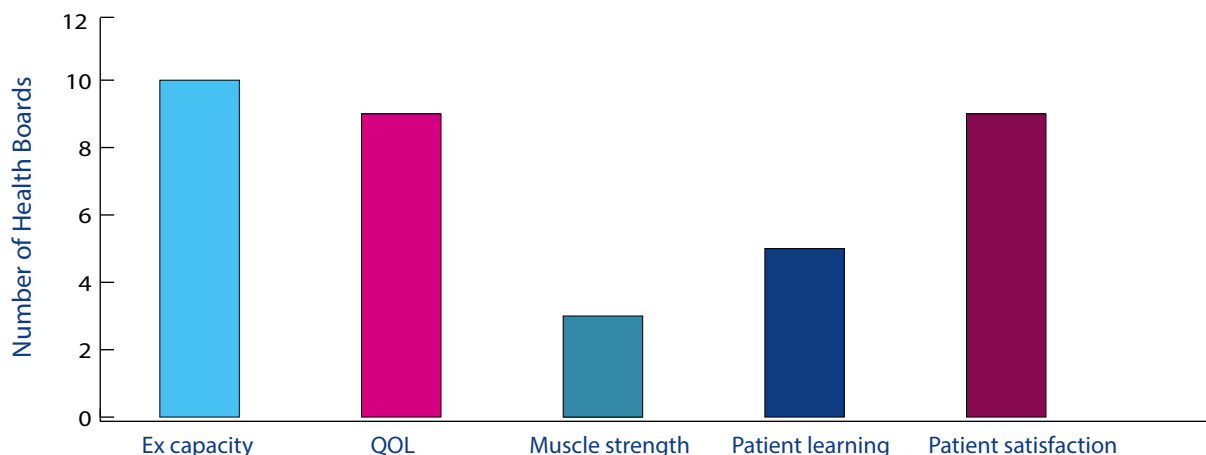


Chart 6: Types of outcomes measured

Across the health boards who responded, exercise capacity (which includes dyspnoea recording) is measured in all cases, and health status (captured by quality-of-life measures) is recorded in 90% of cases. Other measures such as patient satisfaction, patient learning and muscle strength are also recorded but to varying degrees.

- **Two-thirds of PR programmes include longer-term outcome measurement which can evidence the ongoing benefits of PR.**

Encouraging people to remain physically active after completing rehabilitation programmes is vital; the benefits of treatment can be lost within 6-12 months due to many reasons including disease progression, reduced adherence to exercise, exacerbations and co-morbidities³.

Guidance recommends onward referral into exercise maintenance programmes in order to maintain PR benefits^{3,4,9}. In addition, the PARCS report¹⁰ evidenced that PR is an important means of transition from NHS services into the community, and highlights the importance of this transition being part of an integrated pathway.

- **All of the PR services that responded have exercise maintenance options available to which individuals can be referred (although within NHS Grampian and NHS Highland there are some areas where no such support is available).**

The support options available include referring to local leisure facilities, local support groups such as third-sector peer support groups, and innovative support from groups such as gardening and tai chi.

Guidelines also recommend the provision of written exercise plans to further encourage continuing physical activity^{8,9}.

- **Only half of the programmes in Scotland are providing written plans for people as they complete attendance.**

This is in comparison to 74 % of patients receiving written exercise plans in the national COPD audit of services in England and Wales⁸.

Funding of services

The provision of PR services across Scotland has been ongoing for more than 20 years, with varied timescales and levels of initial investment in the service. The majority of services were established with short-term funding from a variety of sources, ranging from 6 months up to 2 years. All of the health boards responding to this survey now have established funding in place, although no information was available for NHS Forth Valley, Orkney or Shetland. NHS Borders remains the only health board which has no funding for PR services in Scotland.

SECTION 2: THE CASE FOR PULMONARY REHABILITATION

The strategic context

The provision of pulmonary rehabilitation services supports the delivery of a number of key strategic drivers in health and social care.

- The Chief Medical Officer's **'Realising Realistic Medicine'**¹¹ supports a holistic approach that puts the person at the centre of goal setting and decision making. This provides a personalised approach to care, and avoids harm and waste in the form of treatments that do not add value. The structure, approach and proven benefits of PR directly align with the key features of this vision.
- Key objectives from the National Health and Wellbeing Outcomes¹² that underpin **'Integration of Health and Social Care'**¹³, as well as the **'2020 Vision and Route Map'**¹⁴, directly align with the aims and proven outcomes of PR. People who undertake PR are able to look after and improve their own health and wellbeing through self-management and live in good health for longer. If adequately resourced, PR can help to address health inequalities, providing highly effective intervention for health conditions with a strong association with deprivation. Evidence shows that PR can reduce hospital admissions while delivering gold-standard intervention in the community.
- By supporting exercise and activity, PR can help to deliver the Scottish government's vision that people living in Scotland will live more active and healthy lives, as set out in **'A more active Scotland: building a legacy from the Commonwealth Games – ten-year physical activity implementation plan (2014)'**¹⁵. Physical inactivity results in around 2,500 premature deaths in Scotland each year, costs the NHS around £91 million annually, and is the second biggest cause of mortality (joint with smoking, behind high blood pressure).
- Health Improvement Scotland published COPD standards in 2010¹⁶ which provided health boards with a toolkit and guidance on how to monitor COPD services, including the provision of pulmonary rehabilitation (standard 4). Despite this, healthcare professionals who lead the delivery of PR services do not currently have information about how their services compare nationally.

Two of the main drivers for compiling this report are the lack of information about PR services within Scotland, and anecdotal reports of significant variation in service delivery, which is at odds with the core aim set out by the Chief Medical Officer to reduce unnecessary variation in practice and outcomes.

There is a lack of nationally-accessible information available within Scotland regarding PR service provision and whether clinical standards are being met, thus limiting the ability to highlight and share areas of good practice. (In contrast, the national COPD audit programme in England and Wales includes PR services.) Information on the delivery methods of services is sparse. This survey goes some way to address these gaps but ongoing, robust data collection would support service providers to benchmark and continue to shape services for the future.

Clinical effectiveness

The evidence of the benefits of pulmonary rehabilitation is well established, with Cochrane reviews endorsing its effectiveness and respiratory guidelines advocating its use the world over^{2,3,4,5,6,17,18}. The Cochrane collaboration has stated that the evidence for PR is sufficient and that further studies comparing PR with conventional care are no longer warranted¹⁷. At a more local level, the 2010 health improvement Scotland COPD standards recommend provision of PR, and the service is supported in the draft respiratory health quality improvement plan under development during 2017¹⁹.

Pulmonary rehabilitation has been shown to help to

- reduce mortality
- reduce hospital admissions
- reduce breathlessness
- improve limb muscle strength and endurance
- improve health-related quality of life
- improve functional capacity
- enhance self-management and knowledge
- increase potential for daily physical activity^{2,3,4,6}

Cost effectiveness

PR is evidenced to be one of the most cost-effective interventions available for people with COPD. The guidelines for this intervention contain evidence that PR can:

- reduce inpatient hospital days
- reduce readmissions
- reduce the number of primary care visits^{2,3,6}

The recent PARCS report¹⁰ demonstrated that there is evidence to support that physical activity (as delivered within a PR programme) can reduce re-admission rates for people with an exacerbation of COPD by 30-40%. It also evidences that length of hospital stay can be reduced by 50% following PR for COPD. Similarly, the NHS England COPD commissioning toolkit evidenced that PR can reduce readmissions within 3 months from 30% to just 7%²¹.

Another significant study showed an overall cost saving of £152 per patient per pulmonary rehabilitation programme, as well as a reduction in the number of hospital stays²².

The Cochrane collaboration also supplies evidence that PR can be cost effective, with evidence to show a reduction in hospital admissions and reduced mortality¹⁸.

The diagram below, included in the Department for Health’s Outcomes Strategy for COPD and Asthma²⁰, illustrates the impact of PR on quality-adjusted life year (QALY) relative to other treatments. (QALY is a measure of the burden of disease on a person’s quality and quantity of life and is commonly used to assess economic value for money of medical interventions. One QALY equates to one year in perfect health.)

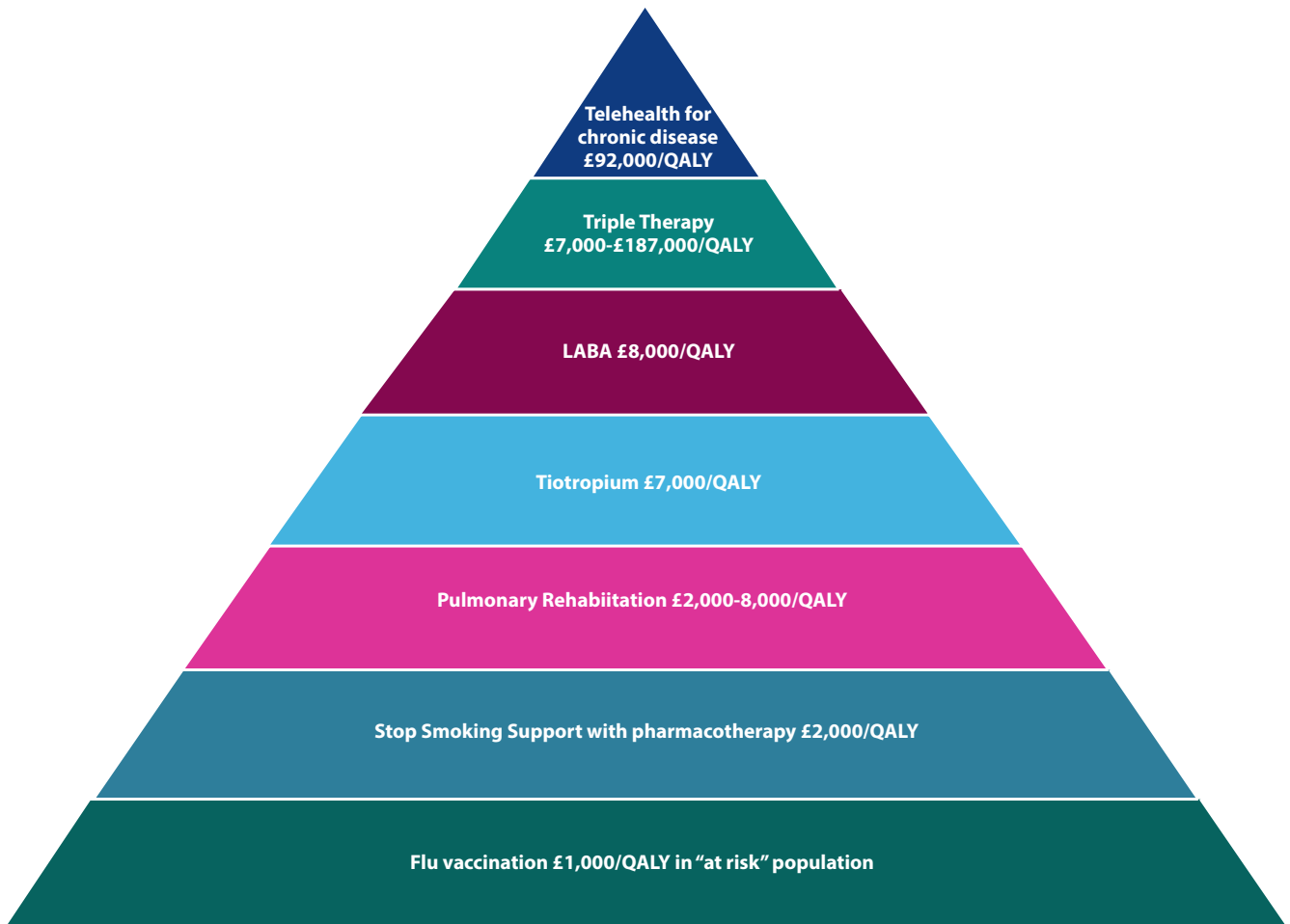


Figure 1: London respiratory team’s COPD value pyramid

(LABA: long-acting beta-agonist)

Putting a definitive figure on the cost effectiveness of PR remains a challenge due to the variable nature of PR service delivery. Although recent costing figures for PR delivery are lacking, a 2007 Audit Scotland report²³ suggested that 4 bed days per person admitted due to a COPD exacerbation could be saved over the following year by completing a PR programme. With a single average bed day estimated to cost £600²⁴, this would mean a potential cost saving of £2,400 per person. Figures from ISD show that in Scotland in 2012 there were 12,162 individuals admitted with COPD; in 2015/16, there were a total of 19,117 admissions¹⁰.

This could offer potential savings of up to £29.2m. Table 4 demonstrates the sliding scale of savings that would still be possible even if the length of hospital stay is reduced because of recent changes in healthcare delivery, such as intermediate care and hospital-at-home services.

Table 4: Potential savings through number of hospital bed days saved, based on number of people admitted with COPD

Potential savings based on:	
4 bed days saved	£29,191,200
3 bed days saved	£21,893,400
2 bed days saved	£14,595,600
1 bed day saved	£7,297,800

These figures are not insignificant; however, because they are based on evidence which is now several years old, there is a need for a re-evaluation of the economic impact of pulmonary rehabilitation within Scotland.

Current challenges in delivery

Despite the clinical and cost effectiveness of pulmonary rehabilitation having been established, a low percentage of the people who can benefit from this intervention actually receive it. In addition to the need for health boards to resource the provision of PR better, there are a number of wider challenges to delivery and take-up of services.

- It is well documented^{2,3,4} that lack of prioritisation and complacency exist around referring people to PR services. In addition, the PARCS project¹⁰ suggests this may be due in part to a lack of understanding and awareness amongst health professionals of the benefits gained from PR intervention, resulting in a lower rate of referrals.
- Attending and completing a course of pulmonary rehabilitation requires support and encouragement for patients. Many people with long-term respiratory conditions are anxious about engaging with any form of exercise programme as they are concerned about increasing their symptoms of breathlessness and fatigue. These fears and anxieties need to be acknowledged and positive messages about the benefits of PR provided at the point of referral and throughout the programme.
- The low completion rates of PR programmes highlight the challenges of maintaining engagement throughout the programme. The reasons for this are complex and varied, but are partially attributable to the volatile nature of the underlying respiratory condition, where exacerbations can hamper attendance.
- Accessing venues can be a significant challenge when someone has reduced exercise tolerance and breathlessness. People struggle to use public transport and the benign task of walking across a car park or down a hospital corridor to get to the location can often prove too demanding. According to this survey, just over a third of PR services are unable to offer any transport. Of those who can, the options are very limited, often with strict criteria that must be met.
- People with more advanced disease are often too frail to attend community-based programmes; the importance of earlier referral needs to be highlighted to health professionals, along with alternative methods of delivering services for those unable to attend classes. Just over half of the services are currently able to offer a home-based alternative.

Identifying levels of unmet need

One of the most striking outcomes of this survey is the consistently high levels of unmet need across all health boards; the best level of provision only offers PR places to 16% of the estimated target population. In calculating the capacity of PR services, the figures provided by health boards have been annualised but do not make assumptions about any breaks in the delivery of services through, for example, unexpected cancellations. The capacity figures in table 2 may therefore be an overestimate, and the level of unmet need even higher.

Whilst it is difficult to quantify accurately the number of people that would benefit from PR each year, this survey has used the established methodology used by Health Improvement Scotland in their 2011 PR costing paper. The figure is calculated as half of the total prevalence and incidence figures; while it may be reasoned that not everyone included in this total would require attendance at PR programmes repeatedly each year, there is currently no standardised method of calculating what a reasonable expectation for this figure would be.

That said, it cannot be assumed that those who have attended once will not need to re-attend at a later date, with the guidelines from NICE 2010 and BTS 2013^{4,5} suggesting that it would be reasonable for a repeat course of PR to be offered to participants after a year of being discharged from a programme, or earlier if their condition indicated it .

Furthermore, this methodology does not take into account the 2013 BTS guideline recommendations that people with COPD with milder symptoms of breathlessness, such as a MRC scale of 2, should also be referred⁴.

In addition, those people living with a long-term lung condition other than COPD are also excluded from the estimated level of need, despite guidelines supporting the benefits of offering PR to people with ILD, bronchiectasis and stable asthma^{4,5,9}. Almost all of the programmes that responded to the survey offer PR to people with other long-term lung conditions such as these. However, as there are no national figures for the prevalence of these conditions the overall target population who would benefit is unable to be quantified accurately.

The potential number of people who would benefit from PR could therefore be far greater than is currently estimated.

Impact of deprivation and rurality

Deprivation

There exists a well-recognised link between areas of increased deprivation and respiratory disease prevalence in Scotland. Higher rates of hospital admissions in people with a diagnosis of COPD occur in areas with higher levels of deprivation, as table 5 demonstrates.

Table 5: Admissions (per 100,00 population) with a principal discharge diagnosis of COPD, Scotland 2015/1625.

	Males 65-84yrs	Males 85yrs +	Females 65-84yrs	Females 85yrs +
1 Most deprived	987.67	1,175.44	1,065.40	987.51
2	642.80	1,516.15	677.01	969.55
3	448.88	1,203.96	453.55	793.13
4	348.47	792.39	319.30	496.45
5 Least deprived	200.37	711.79	199.56	450.31

The regional areas with the highest levels of deprivation are generally found in the central-belt area such as within NHS Greater Glasgow and Clyde, NHS Lothian, and NHS Ayrshire and Arran, as well as pockets of NHS Fife and NHS Forth Valley. Despite this increased need, the current capacity of PR programmes provided by services in these areas still do not reach more than 12% of the target COPD population. Someone living in a disadvantaged area is more than twice as likely to have a long-term condition, such as COPD, than someone living in an affluent area, and is more likely to be admitted to hospital because of their condition.²⁷ This lack of provision reinforces the burden of disease borne by this population and is insufficient to narrow the gap in healthcare provision for the most vulnerable communities.

The survey findings demonstrated no strong correlation between the levels of PR referrals and these disadvantaged populations. This may be due to the limits of the survey, but might also highlight a lack of a targeted approach of the PR services to those living in a disadvantaged area.

The need to target these more deprived populations is further supported by recent evidence from Steiner et al in 2017²⁸ which shows that people living in more deprived areas were less likely to complete a course of PR. Interventions targeted at enhancing referral, uptake and completion of PR among patients living in deprived areas are an important method of reducing morbidity and healthcare costs in such hard-to-reach populations.

Rurality

The challenges of delivering community services within Scotland's more rural areas are well recognised²⁹. It has already been highlighted that accessibility of PR is vital to ensure adequate completion of programmes and that people are less likely to attend if the travel time is in excess of 30 minutes. One potential solution is in the form of advancing technology, resulting in a move to deliver PR to the more rural pockets of the population by using telehealth (as supported by the national telehealth and telecare delivery plan for Scotland published in 2012³⁰). Yet only 3 of the health board areas in the survey are currently using this technology to help overcome issues of capacity and rurality. When providing data in response to this survey, many of the more rural regions

had greater variation within their health board area. This is possibly as a result of the challenges of delivering health services within larger geographical and rural areas. More research is needed into how equitable the service delivery is in the more rural regions.

Conclusion

This survey has provided an opportunity to understand the current state of PR provision across Scotland better, and highlights the key problems of under-provision, under-referral, low completion rates, and the challenges of tackling inequality.

- Despite being an essential component of respiratory management, PR continues to be unavailable in all health board areas. Programmes that exist provide similar content which meets the BTS quality standards but despite this achievement they continue to vary in capacity and delivery, with the number of places available falling far short of the level of need.
- In addition to under-provision, there is a trend of under-referral, possibly as a result of limited awareness of the effectiveness of PR amongst referrers, and further investigation into the cause of under-referral would be useful.
- The number of people who complete their PR programme is significantly low, a reflection of the complex challenges they face, and perhaps an aspect of service provision which needs increased support.
- There is no co-ordinated approach apparent to ensure that PR is made accessible in our more difficult-to-reach communities, be they geographical or social.

Services are working hard to meet the quality standards set out by the British Thoracic Society in 2014; however, some areas struggle to meet these, particularly in offering timely referral post-exacerbation and in providing written plans to support continued activity. The depth of multi-disciplinary teams varies greatly, with only one area having input from a clinical psychologist, despite anxiety and depression being strongly linked with long-term conditions such as COPD.

In order to improve the care of people in Scotland with long-term lung conditions, pulmonary rehabilitation services need increased support. This requires additional provision and effective utilisation of services, broader awareness of the benefits that this treatment can offer (both financial and clinical), and more flexible approaches to delivery to ensure that all those who would benefit can access PR.

This survey was driven by the lack of knowledge surrounding current delivery of PR services; the findings have highlighted a number of areas for improvement and also provide opportunities to share best practice. For PR service to improve there is a need for the creation of a national dataset about the provision of PR. Robust and regular data collection would benefit service users and providers, enabling benchmarking, sharing of best practice, and informing the further development of services.

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Appendix 1: Survey questions

Pulmonary Rehabilitation Services in Scotland, Service Audit 2015-16

Establishment & Funding of service

1. Is there a Pulmonary Rehabilitation(PR) service provided in your Health Board/
Integrated Joint Board (IJB) area?

yes

no

Other (please specify)

2. Please state your Health Board and/or Integrated Joint Board area as applicable.

3. What year did the PR service first begin?

4. Where was the original source of funding for the PR service from?

5. How long did the original funding last?

6. How is the PR service currently funded?

It is absorbed into normal service budget

Change Fund resources

Long Term Conditions fund resources

Scottish Government funding

Service Capacity

7. How many referrals to the service have been made between April 2015-March
2016(inclusive)?

8. How many patients completed the PR programme within the same period?

9. Please define 'completion' e.g 9/12 sessions attended?

10. How many weeks of PR programme are offered to patients?

11. How frequently are classes held?

12. What is the maximum weekly capacity of your PR programme? i.e how many in-

dividuals can atten your programme each week across your health board/ IJB area?

13. What design is the PR programme?

A rolling programme

A block programme

If yes, please give details:

14. Are patients offered transport to and from PR classes?

No

Yes

Other (please specify)

15. Where is the PR programme located?

Hospital based

Community venue

Local Leisure facility

16. How long is the average waiting time for patients from point of referral to being offered an

assessment?(averaged over the year)

Please give details:

17. Is there a mechanism in place to offer patients who have been in hospital, due to an exacerbation of COPD, a course of PR within one month of discharge?

No

Yes

Programme Content

18. What MDT input do you have? (select all that apply)

None

Physiotherapist

OT

Respiratory Nurse Specialist

Doctor

Pharmacist

Psychologist

19. Other than COPD, please list other conditions that your PR programme includes

20. Please provide details of MRC scores of patients attending for PR over the past year?(if available)

How many at level 5 ?

How many at level 4?

How many at level 3?

How many at level 2 or

below?

This information is not available

21. Please give indication of content of the exercise element of the programme? (select all that apply)

static bike?

treadmill/ walking space?

resistance exercises?

Other (please specify)

**22. Please give indication of content of education element of the programme?
(select all that apply)**

Overview of respiratory condition?

Anxiety management?

Breathlessness management?

Inhaler technique?

Explanation of medications?

Energy conservation?

Benefits advice?

Advice on dietary intake or nutrition?

Information about continuing to exercise after completion of PR programme?

Exercise capacity?

Quality of life?

Muscle Strength?

Patient's learning?

Patient's satisfaction?

Other:

23. Please give details of any outcome measures used for the following subjects:

24. Are support workers involved in delivering the PR service?

No

Yes

If Yes, please give details

25. Are telehealth resources used in delivering the PR service?

No

Yes

Other (please specify)

26. Once the programme has been completed, what follow up is provided?

None

Telephone support only

Physically re assessed at a later date

Both telephone support and physical assessment

Please give details

27. Are patients provided with an individualised, written plan for ongoing exercise & maintenance?

No

Yes

If yes, please give details:

28. Is home based PR available as an option in your area?

No

Yes

Other (please specify)

29. What maintenance options are you able to offer patients?

None available in area

Local leisure centre facilities

local CHSS affiliated group

local support group (not CHSS)

Appendix 2:

Health Board	NHS Ayrshire & Arran	NHS Borders	NHS Dumfries and Galloway	NHS Fife	NHS Forth Valley	NHS GGC
COPD Prevalence	10719	2742	4599	9006	6962	31956
COPD Incidence	583	178	304	667	365	1983
Need for PR*	5651	1460	2452	4837	3664	16970
Capacity of programmes	291	0	381	520	unknown	1768
Referrals 2015/16	644	0	200	375	unknown	1985
Completion figures	109	0	107	195	unknown	695
Completion rate	17%	0%	54%	52%	unknown	35%
Waiting times(wks)	6	0	26	12	unknown	2
Funding status	normal service budget	no current funding	normal service budget	normal service budget	unknown	normal service budget

* Based on 50% prevalence & 50% incidence as per HIS 2011 methodology

Appendix 3:

Health Board	NHS Ayrshire & Arran	NHS Borders	NHS Dumfries and Galloway	NHS Fife	NHS Forth Valley	NHS GGC
Post exacerbation referral mechanism	yes	n/a	yes	yes	unknown	yes
Programme design	rolling	no programme	block	block	unknown	rolling
Length of programme	10	n/a	6	6	unknown	6
Frequency	once	n/a	once	twice	unknown	twice
Support worker involvement	yes	n/a	yes	yes	unknown	no
Telehealth used	yes	n/a	no	no	unknown	no
Transport available	no	n/a	yes	no	unknown	yes
Written exercise plan provided	yes	n/a	Yes	no	unknown	no
Follow up assessment	telephone only	n/a	none	none	unknown	none
Home based option	yes	n/a	no	yes	unknown	yes
Other respiratory conditions	ILD Bronchiectasis Asthma PHT	n/a	ILD Asthma Recovering lung cancer Post lung surgery patients.	Pulmonary fibrosis, bronchiectasis, occasionally post-op lung cancer,	unknown	ILD bronchiectasis LAM, lung cancer, post pneumonia

NHS Grampian	NHS Highland	NHS Lanarkshire	NHS Lothian	NHS Orkney	NHS Shetland	NHS Tayside total	NHS Western Isles
10157	6434	17355	17400	372	284	10607	510
804	475	1176	1555	26	14	640	19
5481	3455	9266	9478	199	149	5624	265
570	524	416	1144	unknown	unknown	676	26
537	111	553	1296	unknown	unknown	685	unknown
229	65	123	731	unknown	unknown	382	unknown
43%	59%	22%	56%	unknown	unknown	56%	unknown
7	11	6	8	unknown	unknown	9	16
normal service budget	normal service budget	normal service budget	normal service budget	unknown	unknown	normal service budget	normal service budget

NHS Grampian	NHS Highland	NHS Lanarkshire	NHS Lothian	NHS Orkney	NHS Shetland	NHS Tayside total	NHS Western Isles
mixed	mixed	no	yes	unknown	unknown	yes	no
mixture	mixture	rolling	rolling	unknown	unknown	mixture	rolling
10	6	6	6	unknown	unknown	6	8
mixed	mixed	twice	twice	unknown	unknown	twice	twice
yes	mixed	yes	yes	unknown	unknown	yes	no
mixed	no	no	yes	unknown	unknown	no	no
limited	limited	no	no	unknown	unknown	yes	yes
yes	mixture	yes	yes	unknown	unknown	mixture	no
mixture	mixture	none	telephone & physical reassessment	unknown	unknown	limited	physical reassessment
yes	mixture	no	yes	unknown	unknown	yes	no
bronchiectasis, ILD, pre transplant, post transplant, emphysema, pulmonary fibrosis, anxiety, asthma, asbestosis, alpha 1	bronchiectasis, pulmonary fibrosis, asthma, heart failure or asbestosis	ILD asbestosis, sarcoidosis, lung cancer, lung transplant patients, post MI with COPD, heart failure.	bronchiectasis, pulmonary fibrosis, chronic asthma and any chronic lung disease, pre or post lung transplant	unknown	unknown	Bronchiectasis, ILD, Lung ca - post surgery	nil

Appendix 4:

Health Board		NHS Ayrshire & Arran	NHS Borders	NHS Dumfries and Galloway	NHS Fife	NHS Forth Valley	NHS GGC
Exercise components	Static Bike	✓	n/a	✓	✓	unknown	✓
	Treadmill/walking space	✓	n/a	✓	✓	unknown	✓
	Resistance exercises	✓	n/a	✓	✓	unknown	✓
	Other	Interval training Balance exercises Stretches.	n/a	x	Rowing machine, community venues do not have treadmills	unknown	Walking space (indoors) Pole, step ups, sit to stand.
Education Components	Overview of respiratory condition	✓	n/a	✓	✓	unknown	✓
	Anxiety management	✓	n/a	✓	✓	unknown	✓
	breathlessness management	✓	n/a	✓	✓	unknown	✓
	inhaler technique taught	✓	n/a	✓	✓	unknown	✓
	medication explanation	✓	n/a	✓	✓	unknown	✓
	energy conservation	✓	n/a	✓	✓	unknown	✓
	benefits advice	✓	n/a	✓	x	unknown	x
	dietary advice	✓	n/a	✓	✓	unknown	✓
	maintenance info	✓	n/a	✓	✓	unknown	✓
	Other	Managing chest secretions, managing consultations, staying well and managing exacerbations	n/a	x	Managing exacerbations, info about local Breathe Easy group, Carers centre, travel info,	unknown	Smoking cessation advice, Relaxation, Benefits advice covered as a 1-1 topic
MDT Members	NONE	x	n/a	x	x	unknown	x
	Physiotherapist	✓	n/a	✓	✓	unknown	✓
	OT	✓	n/a	x	✓	unknown	x
	Resp Nurse	✓	n/a	✓	x	unknown	✓
	Doctor	x	n/a	✓	x	unknown	
	Pharmacist	✓	n/a	x	x	unknown	x
	Clinical Psychologist	x	n/a	x	x	unknown	✓
	MDT Other	x	n/a	✓	✓	unknown	✓

NHS Grampian	NHS Highland	NHS Lanarkshire	NHS Lothian	NHS Orkney	NHS Shetland	NHS Tayside total	NHS Western Isles
✓	✓	✓	✓	unknown	unknown	✓	✓
✓	mixed	✓	✓	unknown	unknown	✓	✓
✓	✓	✓	✓	unknown	unknown	✓	✓
step ups, knee bends, marching, leg extensions	Functional exercise i.e sit to stand, lifting, steps	x	stretches; balance/flexibility exs	unknown	unknown	stretching and mobilising during the warm-up and cool down	step ups plus other equipment such as rowing machine if suitable
✓	mixed	✓	✓	unknown	unknown	✓	✓
mixed	mixed	✓	✓	unknown	unknown	✓	x
✓	✓	✓	✓	unknown	unknown	✓	✓
✓	mixed	✓	✓	unknown	unknown	✓	✓
mixed	mixed	✓	✓	unknown	unknown	✓	✓
✓	mixed	✓	✓	unknown	unknown	✓	✓
mixed	mixed	✓	✓	unknown	unknown	✓	✓
✓	mixed	✓	✓	unknown	unknown	✓	✓
✓	mixed	✓	✓	unknown	unknown	✓	✓
oxygen therapy, depression, end of life, chest clearance techniques, support services	x	x	pacing & goal-setting, chest clearance, set back planning and self-management plan review,,; benefits of exercise including home exercise diaries	unknown	unknown	Planning ahead - ACP discussion, travel, sputum clearance, managing exacerbations, smoking cessation, chest clearance, benefits of exercise	x
✓	x	x	x	unknown	unknown	x	x
✓	✓	✓	✓	unknown	unknown	✓	✓
✓	x	✓	✓	unknown	unknown	✓	x
x	✓	✓	✓	unknown	unknown	✓	✓
x	x	x	✓	unknown	unknown	x	x
✓	✓	x	✓	unknown	unknown	x	x
x	x	x	x	unknown	unknown	x	x
✓	x	x	x	unknown	unknown	✓	✓

Appendix 4 continued:

Health Board		NHS Ayrshire & Arran	NHS Borders	NHS Dumfries and Galloway	NHS Fife	NHS Forth Valley	NHS GGC
Location of programmes	Hospital based	✓	n/a	✓	✓	unknown	✓
	Community venue	✓	n/a	✓	✓	unknown	✓
	leisure	✓	n/a	✓	x	unknown	✓
Outcome measures	Exercise capacity	✓	n/a	✓	✓	unknown	✓
	Quality of life	✓	n/a	✓	✓	unknown	✓
	Muscle Strength	✓	n/a	x	x	unknown	x
	Patient's learning	✓	n/a	x	x	unknown	✓
	Patient's satisfaction	✓	n/a	occasionally	occasionally	unknown	x
	OM Other: Confidence to self manage (0-10 scale)	Confidence to self manage (0-10 scale)	n/a	x	x	unknown	x
Maintenance Options	None available in area	x	n/a	x	x	unknown	x
	Local leisure centre facilities	✓	n/a	✓	✓	unknown	✓
	Local CHSS affiliated group	x	n/a	✓	x	unknown	x
	Local support group (not CHSS)	✓	n/a	x	x	unknown	✓
	Other	SM Programme	n/a	Tai chi group	x	unknown	x

NHS Gram-pian	NHS Highland	NHS Lanark-shire	NHS Lothian	NHS Orkney	NHS Shetland	NHS Tayside total	NHS Western Isles
mixed	✓	✓	ü	unknown	unknown	✓	✓
mixed	x	x	ü	unknown	unknown	✓	✓
mixed	x	x	x	unknown	unknown	x	x
ü	mixed	✓	✓	unknown	unknown	✓	✓
ü	mixed	✓	✓	unknown	unknown	✓	✓
mixed	mixed	x	✓	unknown	unknown	x	x
x	x	x	✓	unknown	unknown	✓	x
mixed	mixed	✓	✓	unknown	unknown	✓	✓
x	x	x	x	unknown	unknown	MRC status	x
mixed	mixed	x	x	unknown	unknown	x	x
mixed	mixed	✓	✓	unknown	unknown	✓	✓
mixed	mixed	x	✓	unknown	unknown	✓	x
mixed	x	x	✓	unknown	unknown	✓	x
x	x	x	various 3rd sector activity programmes	unknown	unknown	allotments	walking groups



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